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ABSTRACT

The paper details the impact of blindness and visual impairments on young children's development. Specific developmental risks are examined for the following areas (sample difficulties in parentheses): body awareness (delayed concept of object permanence), motor development (lack of incentive to explore and resultant delay in purposeful movement), auditory awareness (problems in acquiring good listening skills), language (lack of opportunities for indirect initial introduction and reinforcment of vocabulary, concepts, and descriptions), cognitive development (use of inappropriate tools for testing), and psycho-social development (adult overprotection and lack of experience on which to base social skills). The impact of hospitalization are enumerated and suggestions are offered for reducing negative results for both verbal and nonverbal visually impaired infants and toddlers. Considerations specific to recently blinded children are also examined, including the child's needs for calm conversation and positive physical input. (CL)

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THE VISUALLY IMPAIRED PRESCHOOLER WITH AN EMPHASIS ON MEDICAL INTERVENTION

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In Memory of George Kelso, MD

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Pediatric patients with severe visual handicaps have special needs, which complicate the care of a specific illness for which they are hospitalized. Caretakers must consider the TOTAL child in order to reduce the number of adverse affects which occur when children are hospitalized. Pediatric care should be approached from the PERSPECTIVE of the blindness.

Medical maneuvers are stressful to all children--the affects are exaggerated in young visually impaired patients. Strangers in the unfamiliar surroundings of a pediatric clinic poke, probe, and occasionally give injections or perform other uncomfortable procedures. Add the disquieting effects of separation from the parent when the child is hospitalized and the traumatic experience is often overwhelming. The visually impaired child, especially congenitally blind, can be severely upset, even during a relatively short confinement in a hospital. Such experiences can result in a dramatic regression of development for the visually impaired child following hospitalization.

With the incidence of blindness in the pediatric population documented at about 8 per 10,000*, most hospital staffs lack experience in handling visually impaired children or make unwarranted generalizations based on a limited experience with one blind patient.

Those working regularly with congenitally blind infants and preschoolers know that for this population no single cognitive experience goes undistorted.* Awareness and understanding of self, others and the world depends upon comprehensible exposure to stimuli. When one realizes that vision is the primary integrating sense,* the risks affecting the development

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of a meaningful cognitive foundation are understandably high, and determined by experiential limitations. Anything that inhibits or interupts the input, reception and interpretation of the blind child's experiences can dramatically interfere with developmental progress. Therefore, precautions have have the potential of decreasing the negative impact of necessary, but unpleasant events in the blind child's life are of extreme importance.

The first portion of this paper focuses on the perspective of the congenitally blind child. The purpose is to promote an awareness of the complex dynamics contributing to the child's ability and motivation to build a foundation for learning and for participating in the world

In the second half, the impacts of hospitalization are enumerated and suggestions are offered for reducing negative results for both verbal and non-verbal visually impaired babies and preschoolers.

THE EFFECTS OF CONGENITAL BLINDNESS ON "NORMAL" DEVELOPMENT

The impact of life's experiences on the total child during the formative preschool years is obvious. If development is to proceed within the wide range of "normal," the child needs to acquire a good foundation for learning. The establishment of this foundation is in direct correlation to the child's exposure to stimuli and the ability to internalize and process information received through all of the senses.

The significance of a deficit in the sense of sight cannot be measured. It has been estimated that up to 80% of learning* takes place through vision. Even if the child is "only" blind, with no other disabilities, normal progress in developmental areas is at risk. The problems of the negative impact are

further magnified if there are additional handicaps.

It is understood that the unique and often tragic effects of visual impairment during the early years are influenced by numerous variables. For example, etiology, age of discovery, prognosis, additional handicapping conditions, general health, number and duration of hospitalizations, all contribute to the total developmental dynamics. Family circumstances, including the initial impact and reaction to having a blind child, the family constellation and support system, and background and cultural influences are all significant. Social and psychological aspects such as community and peer attitudes, the child's language and communication skills, and the child's concept of self, can have a major effect upon development. Intervention by professionals differs in availability, type, intensity, focus and parental involvement. These and other variables have the potential to affect the blind child more demonstrably than they would sighted children.

The impact of these variables can be reflected in the blind child's progress in areas crucial for subsequent learning.

SPECIFIC DEVELOPMENTAL RISKS

1. BODY AWARENESS: Unlike the sighted child who sees other people's bodies and how they manipulate them in the environment, and who can visually compare the similarities of the physical attributes and motions, the blind child can only begin to form these associations by "hands-on" involvement. It has been noted by Bryant Cratty that, "The body image of the child is the real substance of the child. If the sightless child does not know the nature of the space he occupies, and the manner in which he can move and the names given to his body and its parts, it is unrealistic to expect a blind child, in the absence of efficient space organizers (the eyes) afforded the sighted, to organize space and to learn about space without a thorough and systematic effort made to educate him about the dimensions of himself and his world."*

This child, who is deprived of the comparative "picture" of other human models, and who is missing visual stimuli to motivate him to get involved with the world "out there" in ways that will help him to naturally discover the capabilities of his own body, needs direct, purposeful and consistent informational input to facilitate internalization through other modalities. A 1½ year old anophthalmic toddler, for example, who had never pulled to a standing position even in the crib, was actively put through the entire process, from placement of the hand on the rail, to step by step repositioning of her legs and feet. After only a few demonstrations, the child could do it alone, and within a week, she was pulling up to standing throughout the house. Another totally blind child, age 4, was having difficulty pulling on pants. The legs of the pants would invariably fold over the foot and get "stuck." When she was told to "move her foot" to work it through, her literal interpretation led her to move her foot laterally, in conjunction with the entire leg, which did not solve the problem. It was only after she was guided in how to move various body segments in relation to each other that she could focus on moving her foot at the ankle and successfully ease it through the pant leg.

Development of the concept of object permanence is delayed in blind children. Without proper attention, "The Good Fairy Syndrome," of the thought that things come from nowhere and go to nowhere, may even persist beyond the age of two. Selma Fraiberg noted that, "The blind infant, then, has a fragmentary and discontinuous experience with objects...and probably can evolve a concept of the independence of objects from his own perceptions only after his own locomotion provides him with spatial references and repetitive experiences with object finding."* At the same time, movility is generally delayed, which perpetuates the cycle.

2. MOTOR DEVELOPMENT: It is normal for the early motor milestones of the visually impaired to be behind those of

sighted peers. This is understandable when one considers the role of vision in motivation for movement, curiosity, and initiation of imitation. The sighted child sees things to reach for, is rewarded by contact, and tactually explores to confirm and reinforce visual messages. This natural incentive provides the practice needed for proficiency.

It is also recognized that ear-hand coordination in normal babies is demonstrated later than eye-hand coordination. However, without vision promoting undirected association with auditory cues, even purposeful movement towards soundmaking objects may be delayed. Unless the blind child is directly introduced to things "out there" to go for, and how to do it, his random encounters may not provide enough consistent input for the reinforcement necessary to form generalizations, and thus initiate the associated motivation to check out the world.

Mobility for the blind child has additional risks. Until he has tied together orientation clues, he may be subject to a high failure-success ratio of hit and miss. In fact, the crawler, leading with his head, will receive a lot of discouraging hits that may outweigh the desire to move out. Free walking is very threatening, too. The prone position provides the security of lots of contact with the world. While the sighted child maintains this contact through vision, the blind child loses much of it when standing, until he has thoroughly established spatial awareness and the sense of object permanence.

The situation is compounded if the parents are anxious or over-protective. The child often senses their anxiety and may also exhibit over-dependence on them for interpretive information, rather than learning to "read" his own messages. A mother of a 13-month old RLF baby, for example, noticed that he didn't move around when she was out of the room. This concerned her because during this time he did not appear to be interested in the things around him, and instead seemed to turn inward and

was starting to rock and demonstrate patterns of self-stimulation. She thought this pattern might be related to the fact that her presence provided him with eyes: she always said, "Watch out" when he was about to bump into something. The mother decided to wean him from dependence on her for "warning," and actively presented highly motivating objects where he would have to "go for them," such as a cookie on the table, or his bottle on the chair. She limited her input to the motivating object, and encouragement, and veiled her anguish at his frustration. Her efforts paid off, as the child quickly gained confidence and developed astonishing accuracy in crawling directly toward objects, stopping sometimes less than an inch before head contact, and then reaching out with his hand. Soon he was exploring the entire house and seeking her out in other rooms.

Fine motor activities are less spontaneous for blind children. They cannot observe the total process at one glance, and may be unaware of all of the fascinating cause-effect opportunities waiting for a twist, pull, push, squeeze, poke, lift, etc. New knobs, buttons, switches, twist caps, and lids may remain unexplored unless and until the child has had enough exposure to incorporate purposeful scanning skills as a basis for generalized curiosity. Often, though, if the child has careful "hands-on" demonstration of a process, and if it's purpose is applicable to him from his perspective, he may readily catch on. In one case, a "retarded" blind 4-year old, with severe Cerebral Palsy, learned how to turn on the radio and fine tune it to his favorite station. It is worth noting that the child's pleasure in achieving this later became a functional medium for use as a reward to complete less motivating tasks.

3. AUDITORY AWARENESS: Contrary to the popular belief that the sense of hearing is inherently better in blind than in sighted people, acute listening skills must be developed. Real meaning has to be actively tied to sounds in a way that makes purposeful listening useful from the child's viewpoint. However, learning to extract pertinent sound clues from a continuous flow

of noise without vision to verify the applicability of the information, is a difficult process. Confirmation may not be consistent. The sighted child, for example, who hears the refrigerator door open may "look" to see if Mama is getting his bottle. The blind child may not tie the sound to something that he might become involved with because there are too many other times that the door opens and nothing happens that involves him. In effect, the noise may remain buried with other unrelated noises in his life, and the value of associative catagorizing could continue unexercised, until he has acquired enough comprehensible input for a basis to attend.

Though auditory awareness can facilitate orientation, mobility, and motivation to get involved, acquisition of good listening skills does not come easily. Sounds, such as wind chimes, clocks and refrigerator motors, are often picked up by the blind child who learns to recognize where he is in relation to such noises, and can use the information to move out more freely. However, sighted adults, who tune out such sounds, may not recognize that they are interfering with the input when the radio, TV or other background chaos drowns out the more subtle, yet consistent clues. In fact, too often, blind children are allowed to occupy their time by listening to taped recordings repeatedly, because the child seems content, and it "keeps him busy." Unfortunately, the child is actually being allowed to withdraw from the rest of the world, and to perseverate on a non-productive activity. With the tape occupying his audio focus and without vision to draw him outward, his attraction to external stimuli is very limited.

Comprehensive differentiation of sound, in association with the cause, is complex, especially if the foundation for communication is not yet established. Even when associations are made, total understanding may not be complete. A 4-year old anophthalmic child illustrated this one day, when he walked around the kitchen with a wooden spoon, banging on pans, hitting the stove, and dragging the spoon on the counter. When asked what he was

doing, his reply was: "Well, don't you know? I'm cooking!" To him, the sounds were right, but in reality, the action was not.

Another 4-year old totally blind child, riding in the car, asked "What's that?" when the regular rhythms of the ride were changed. She accepted the reply of railroad tracks and even recognized when they crossed some more. The driver asked if she knew what railroad tracks were and she could only describe them as "bumps." Further quizzing about sounds that the child recognized during the ride, from the clicking of the turn signals and the windshield wipers, to potholes and raised reflectors on the highway, revealed that she had internalized only word labels with the sounds, but had no concept of how, or why the noise was produced.

In both cases the children described were playing "mind games" with sound. One was trying to reproduce it for association and the other was categorizing by label for accuracy. In effect, they were each testing their listening skills and finding them useful. Fortunately, with the advantage of being able to communicate, others could share, clarify and reinforce with extended related experiences for greater total understanding.

4. LANGUAGE: The blind child does not have the natural chance for indirect initial introduction and reinforcement of vocabulary, concepts and descriptions. He may not see the exchanges that take place through verbal communication, which teach the value of expressive-receptive communication. In effect, he is deprived of the subtle opportunity to apply the "4-C's": Compare, Categorize, Comprehend and Communicate. A direct focus toward developing language skills is a must in providing key wording, labels and the ability to use language appropriately.

The challenge is apparent when one recognizes that the blind child cannot take in total objects and their functions at one

glance. Observation is limited by the established foundation and opportunity to place together clues received by his other senses...often the fingertips alone. How many different chairs does it take for the child to "actively" experience, for example, before he can generalize "chairness" when he is in a new environment? How much exposure to different kinds of balls: nerf, tennis, soccer, golf, etc., - is necessary to establish the concept of "ball?" But what about a football, or an orange?

The real questions that must be asked, therefore, is what experiential opportunities has the child had to develop a useful and comprehensive language foundation. Recently, a consultant visited a class for "exceptional children." The main concern was that they were having little success with the blind children in the language portion of the program. It was observed that they presented plastic miniatures, such as cows, and asked the blind child to identify them and then locate and name various parts, like the ears and feet. However, the toy cow was only a cow to the sighted, with visual association. Even if the blind child had an opportunity to experience the actual animal simultaneously, relationship to models is unrealistic. The unrelated guessing centered around the reply presented success-failure risks that could inhibit participation. The exercize would have been far more appropriate if the object had been presented as a piece of plastic that felt cool, and had humps and ridges, providng the child with words to relate to similar experiences.

A good reservoir of meaningful vocabulary, however, does not assure that the child understands the dynamics of word power and can apply it to purposeful communication. It takes repeated, active experiencing for the blind child to begin to comprehend the cause-effect impact of verbal exchange. Even then, he must draw from his limited foundation and sift information from a world of phrases that can mean nothing at this time. Think, for example, of the foundation and complex mental

process needed for a congenitally blind person to fully understand the simple phrase, "Turn on the light."

It is no wonder that visually impaired children sometimes present patterns of stimulus-response, one-word answers, echolalia, and meaningless repetition. On one occasion, a 3½-year old who demonstrated all of these patterns, and who had never initiated a conversation beyond one-word commands, such as "potty" or "drink" was speaking in complete and appropriate sentences after three weeks in a carefully selected preschool program. The opportunity had provided him with language models, information to share, and a purpose for talking because his peers wanted to play real games, and not the one-on-one guessing games that his adult-oriented world had fostered.

5. COGNITIVE DEVELOPMENT: It is difficult to assess the cognitive foundation and potential of a blind child. Obviously, without vision to synthesize messages, there are risks in gaining comprehensive experiential exposure with the necessary extended reinforcement for internalization and generalization. Assuming that a child CAN'T do something, therefore, must always be overshadowed by the question of whether he has had enough logical, sequential introduction to tie things together. In contrast to sighted children who are visually drawn outward, the blind child's motivation to get involved with the world is heavily influeced by the expectations of others. If, for example, a child has always been fed, yet doesn't see others in the process of eating, and has never been put through the motion of bringing a spoon to his mouth, how can he understand what is expected? He is dependent on others to believe in him, and actively work with him, before he can demonstrate his capabilities.

Accurate cognitive assessment of the blind child is also complicated by use of inappropriate tools, and the application of incorrect labels, such as "Autistic." To often, familiar,

highly visual tests, based on sighted norms, are administered to these children by professionals with little or no experience with congenitally blind and with little knowledge of the impact of severe visual impairment. Subsequently, many blind children who may have reached a developmental plateau, not for lack of ability, but rather due to experiential deprivation, lack of motivation for application of skills, or withdrawl into their own world in response to negative or confusing situations, are in programs with sighted children who function at a lower level because their potential really is low. The tragedy is that without role models, real expectations and input by those who understand the perspective of blindness, the child's opportunity to grow may remain very limited. "The result would be that a normal child who was slow to develop in some areas would become a child who is severely retarded in many areas."*

6. PSYCHO-SOCIAL DEVELOPMENT: The social and emotional needs of severely visually handicapped children are more differentiated than for those children with vision. Their reliance on others to provide a comprehensible foundation about a world that they cannot see to organize independence, brings unique problems. Unable to rely on incidental learning by observing other children, the blind child's first years are primarily centered around adult-child interactions. The symbolic relationship between the blind child and the primary caretaker is more intense than any other human relationship and the variables are virtually immeasurable. Thus, a realistic identification of self in relationship to other, the world, and as a significant individual has a tenuous beginning.

The extent to which the child gains and uses information not only depends on logical input from his perspective of interpreting without vision giving the full and immediate picture of the experience, but also requires REAL expectations of others. Blind children, for example, can be processed through self-feeding, but what is the motivation to become an independent "doer," rathern than a "done-to?" The frustration and mess

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during the learning period is not balanced by the desire to mock visual models, illustrating that practice will lead to proficiency. The self-concept component of successfully emulating others is missing and often the opportunity to realistically "earn" self-esteem by "doing" is not as apparent to the child.

Adult over-protection or using the child's blindness as an excuse for not expecting independence can be detrimental. This was demonstrated when three totally blind boys, ages 5, 6 and 7 were enjoying a field trip to a farm. At lunch-time, the 5-year old asked, "Will someone please feed me?" At that point, the other two boys thought he was a "baby" and resorted to rejection tactics. Later, when the mother was confronted with the problem, she said that she still fed the child when she was in a hurry...which was most of the time. The child was reflecting what he felt was acceptable behavior and he did not have the tools to assess that this was inappropriate behavior in this situation.

The experiential foundation necessary to develop the skills for interpreting social situations is extremely complex without vision to integrate the total scene. For example, a bright severely low-vision girl, who was in a regular preschool, followed the teacher's directions to "go around in a circle," by pivoting in one spot, while the rest of the children used further visual clues and went in a large circle as a group. Fortunately, this child was comfortable with her difference,

and readily accepted correction in a way that did not evoke reactions from her peers.

In addition to the extended adult dependency, often the blind child's social skills are delayed because they need more time to develop a concrete foundation based on REAL experiences. Much of their world is not yet understood. Thus, imitation play and the symbolic transfer of functions of real objects to toys is delayed. This, in turn, interferes with normal play-patterns and interactions with peers, who do not yet understand the implications of blindness. Obviously, any experiences that interfere with the trust factor that is VITAL for these children, who are so dependent on the human component to give them essence and to draw them out into the world, must be minimized when possible. This is a very delicate population.

With the thought that no learning experience is of any more value than its real application to the child's life, it is vital for us to keep the blind child's perspective in mind when we consider the TOTAL development of the child.

BLIND BABIES NEED SPECIAL HANDLING

It is known that for blind babies, a stay in the hospital of less than one week can produce tragic adverse effects. They can quickly become withdrawn and "turn off" the outside world because they are unable to receive visual clues that help to sift safe situations from those which warn of impending

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discomfort. This tends to inhibit development of their curiosity and desire to reach out (which is a major incentive to become an active participant in this world.) These babies are not just in a dark unfamiliar place. They are in a void surrounded by meaningless sounds, smells, sensations thathave no foundation for associations to take place.

"SPECIAL HANDLING" CHECK-LIST FOR INFANTS

1. POST A SIGN on the bed reminding those interacting with the baby of the visual impairment.
2. ADDRESS THE BABY BY NAME, or "nickname" when approaching. This will give the cue that the baby is to be "part of the action" of what is going on, so that he may concentrate on other related clues in effort to understand what is going on.
3. ESTABLISH A CONSISTENT DISCOMFORT INDICATOR, like a gentle "flick on the heel," allowing the baby to know that the following activity (shot, thermometer, etc.) will not be pleasant. This may prevent generalized withdrawl from all physical input, so that the baby will remain receptive to the much-needed positive human contact.
4. PROVIDE AS MUCH DIRECT HUMAN PHYSICAL CONTACT as possible. Blind babies develop awareness of "object permanence" because it is actively taught ("hands on".) Therefore, the only real associations that very young babies have established are centered around people contact...and this can be lost without reinforcement.

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5. TALK to the baby. Even though the words are not understood, the sounds indicate interaction.

6. GENTLY MASSAGE the baby, describing parts of the body being touched and letting him receive warm strokes of love while at the same time becoming aware of his body image. Blind babies have less kinesthetic and proprioceptive input than the child who is visually attracted to turn and look, thereby stimulating parts of his body through movement.

7. HOLD THE BABY OFTEN, if possible, so that he will recognize that he is <u>part</u> of the world and not a world within himself.

8. WHILE FEEDING, hold the baby so that the "Good Fairy Syndrome" (the thought that things appear from, and disappear to, nowhere) won't be prolonged and he will have the opportunity to experience some of the action involved in the feeding process. Also learn about the child's normal feeding habits. If the baby can't see, and hasn't been exposed to spoon-feeding or has a resistence to textures being put in his mouth, the experience can be traumatic. GO EASY.

9. GENTLY TUG the baby's hand before presenting an object. This may help to establish the concept and motion of reaching out.

10. GUIDE HIS HANDS to feel different textures. This may help prevent him from losing his tactual curiosity. For the blind child, however, who is not conditioned to enjoy touching, this can be a negative experience. GO SLOWLY.

DON'T WORRY ABOUT OVERSTIMULATING THE BLIND BABY. He needs all of the positive interaction he can get!

BLIND TODDLERS ALSO NEED SPECIAL HANDLING

"Normal" blind preschoolers have started to develop an associative foundation for understanding the world around them. They are aware of "object permanence" and have started to recognize a cause-effect aspect of life. Their mobility has rewarded their curiosity to know what is happening "out there" and verbal descriptions can have meaning. Total withdrawl with this group is more tragic when it happens because it represents rejection of the world to which they have been introduced and is not the result of lack of awareness of what it is about.

A "SPECIAL HANDLING" CHECKLIST FOR TODDLERS

1. ALWAYS ADDRESS the child by name, or established "nickname," as you enter the room, even if you are just passing through. This will reinforce the sense of HUMAN CONTACT and reduce the feeling of isolation.
2. EXPLAIN what you are doing (ie: pouring water, taking pulse, writing on chart.) As the scene is repeated, he will become aware of patterns and may start to understand what is going on. This may reduce some of the fear of the unknown.

3. WARN the child when he will be subjected to discomfort (a shot, removal of tape, etc.) so that he will not be surprised and develop generalized fear.

4. DESCRIBE his room and changes as he is moved from his surroundings (such as when going for X-rays, etc.) so that he can work on associative clues, rather than "turn-off" the maze of incomprehensible input.

5. ACTIVELY INTRODUCE, step-by-step ("hands on") such things as food on the tray (where positioned, and how to open containers,) the call button (how it works and its consistent location,) the bathroom (toilet, paper, sounds, etc.) This will help him to recognize that he can still exercize some independence and be part of the cause-effect of some of his world.

6. WALK the child often, if possible. Without vision, he develops space perception through mobility. Lack of such mobility may contribute to withdrawl.

7. PROVIDE REASSURANCE and let him know why certain things are necessary. Even if he doesn't understand, the honest, straight-forward tone of your voice will reassure him that it must be all right. For example, if the child is not in a crib at home and is suddenly surrounded by bars, he may feel trapped and isolated without an explanation.

8. MINIMIZE use of TV, radio or other artificial sounds, so that the child may work on understanding and categorizing the "real" sounds.

9. DO NOT talk about the child's condition in front of him. He takes in more than is reflected in his expressions.

DON'T WORRY ABOUT OVERSTIMULATING THE CHILD. Established attachments are more intense than those of sighted children. The sightless are more dependent on others to introduce and help interpret the world. Adverse effects of separation from family and familiar surroundings are intensified by blindness. The child needs lots of reassurance.

HOW ABOUT RECENTLY BLINDED CHILDREN?

1. Blindness is not just a loss of sight but also a loss of subtle visual input, such as glances of approval indicating "Hey, you're all right." The child needs lots of extra POSITIVE PHYSICAL INPUT.
2. The child has not yet developed the ability to "read voice inflections," but constant CALM CONVERSATION will reduce fears.
3. The child may exhibit extreme anxiety at being left alone, due to the totally isolated feeling of being without sight. Help him to recognize the clues that will help him to know that he is not alone.
4. The child has not yet developed the ability to use meaningful tactual exploration and may even exhibit tactual defensiveness because his "visual memory" has already recorded negative things out there. Introduce objects to explore

and ask the child to describe the experience to promote thinking from the perspective of touch. Go easily, though.

CONCLUSION

Awareness of the impact of visual impairments on the pediatric population and responding to the differences CAN make a difference.

E N D

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